

2. Cancer Narratives as Ethnographic Sources

The cancer narratives analysed in the current work are the results of the writing process. Even if the respondents have tried to compose a coherent and meaningful story, full of emotional turns, only a few of them succeeded in doing so. Adopting the suggestion made by Dell Hymes, the American sociolinguist, the process of composing thematic writing is comparable with oral performance, where everyone can speak, but only few have communicative skills suitable for entertainment (Hymes 1974, 75). From the stylistic point of view, written cancer narratives stand between the oral and written tradition of self-expression. The letters that accompany the cancer narratives express the fact that, on the one hand respondents tried to describe the events experienced as accurately as they appeared in everyday life (060, 569), while on the other hand, they were aware that over time the painful experience faded in their memory, so they cannot be entirely accurate (099, 101, 354, 363, 396, 507, etc.). The writing process itself is also complicated as it forces the participants to choose between relevant and irrelevant themes (236, 267, 397, 401, etc.). For this study, however, the literary quality of the texts is not important; more important are the facts preserved by the cancer narratives, via the writing competition, and the fact that this creates a context that represents popular ideas regarding cancer that mediate the everyday life of Finnish cancer patients. Therefore, I approach the cancer narratives as ethnographic texts, which according to Mikhail Bakhtin, are definable as “literary but extra-artistic authorial speech” (Bakhtin 1981, 262). In my opinion the characteristic ‘extra-artistic’ does not diminish the value of can-

cer narratives as an ethnographic source, while the collected writing allows study of the cancer experience on the individual, sociocultural and societal level using the narrative approach.

Cancer patients' writings about their illness may be approached as "basically believable" and "near" to individual experience (Garro & Mattingly 2000, 260; see also Goldstein 2004, 157–177). Therefore, I wish to analyse the narrative composition as a series of choices influenced by numerous internal and external aspects. Firstly, the individual "verbalisation" or "textualisation" process is affected by an individual's ability to memorise and remember (Lehmann 2007, 50–57; Honko 1998, 59; Lord 1987, 307). Secondly, people select events and episodes from among the vast range of possibilities in the flow of experience, and then present them in an order which itself intentionally or unintentionally conveys significance (Garro & Mattingly 2000, 260). Thirdly, narratives as representations always contain some kind of particular goal (Jakobson 1960, 351), and carry certain culturally defined functions (Bascom 1954, 337–338) as well as individual intentions affected by the context (Siikala 1990, 90–91). To demonstrate the value of cancer narratives as a research object, it is important to examine the rules of narration, which affect the construction of thematic writing, and analyse the possible influence of the individual and sociocultural aspects that influence the composition of narratives.

The 'motivation' to write

The written manner of self-expression is very common among Finns (Salmi-Niklander 2004, 42–44). Since writing skills were introduced to Finland, the preservation of personal memories and experience has become a part of everyday life (Makkonen 2002, 9–11). Because of the historical practice of collecting oral tradition, Finns are used to participating in the writing competitions organised by folklore archives (Pöysä 2008, 223–228). However, written individual experiences and reminiscences have only been accepted among ethnographic sources recently. Not too long ago, such materials were evaluated by folklorists as a nuisance to folklore archives (Latvala 2005, 27). Today the situation and attitudes have changed, and written (not only autobiographical) narratives have gained high value among Finnish folklorists as ethnographic sources dealing with personal experience.

I would like to discuss the respondents' motivations for writing and contributing their experience to the archives. The writing competition is only secondarily important for writing down personally significant experience, thoughts and feelings. Of far more importance has been the opportunity to 'talk' about multiple issues relating to cancer as it is experienced by individuals:

Olen myös kiitollinen tämän keräyksen järjestäjille, sillä he antoivat minulle sysäyksen ryhtyä kirjoittamaan, Olen nyt ensimmäistä kertaa seurannut yhtä sävellystä 'elämäni' johdonmukaisesti läpi yhden soitimen – syöpä – osalta. Partituurin tutkiminen on ollut raskasta mutta hyvin antoisaa. Olen päässyt lähemmäs itseäni ja löytänyt paljon yllättäviäkin sävelkuvia.

I am also grateful to the organisers of this competition because they gave me a reason to write. This is the first time I have analysed one composition in my life through one instrument – cancer. Studying the text has been a hard, but very giving, experience. I have become closer to myself and discovered many surprising things about myself. (202)

On ihan hyvä, että tällainen kirjallinen "mitä kuuluu" kysely on järjestetty. Minä ainakin olen paperille paljastanut nyt sellaisia tunteja itsestäni joita en keskusteluissa ystävillekään kerro. Kaikkia kipeimpiä edellä kerrottuja tuskin vaimollekaan. En ainakaan tässä vaiheessa. Meillä on luottamukselliset välit, mutta yritän säästää häntä sellaiselta mikä sattuu eikä ole välttämätöntä kerrottavaksi.

It is really good that this kind of 'how are you' exploration has been organised. I have revealed in the paper the kinds of feelings about myself that I do not go into when talking with friends. Most of the painful memories I have hardly told my wife. At least not yet. We trust each other, but I try to save her from things that are not necessary to tell. (508)

Oheiset liuskani ovat kooste vuosien varrelta erilaisista muistiinpanoista. Olen liian väsynyt jaksakseni kirjoittaa niitä kaunokirjallisempaan muotoon. Haluan vain tuoda julki elämässäni päällimmäisenä olevan tuskan ja liian raskaat päivät, jotta tekstini tulisi mahdollisesti palvelemaan ja ehkä estämään ketään muuta joutumasta samanlaiseen kurimukseen.

The following pages are a summary of different notes made during past years. I have been too tired to write them in a more literary style. I just want to bring out the spleen ruling my life and my too-hard days, so that perhaps the text can prevent others from ending up in similar torture. (363)

Participants said that writing is a good way of expressing oneself. Therefore they began to make notes about their illness experience while still in hospital. Such writing becomes a way to keep track of daily concerns in a situation that is affected by physical sufferings and inner confusion. Thus, respondents say that the act of writing helped them to clear their thoughts and bring structure to “the mess in one’s head” caused by the illness: *”Mutta teki hyvää kirjoittaa. Nyt sitä voisi taas jatkaa – omaksi iloksi.”* “Writing made me feel good. Now I could continue with it – just for my own benefit” (334). Or, *”Ellen osaisi kirjoittaa tunteitani ulos en tiedä montako astiaa olisi särkynyt. Kynät ovat sentään astioita halvempia ostaa.”* “If I could not express my feelings in the written manner, who knows how many dishes would be broken. Buying pencils is anyhow cheaper than buying dishes” (381).

Writing down experiences and thoughts also aids the memory. The inner confusion (caused by illness) may be so great that everyday life and events just slip away. Respondents who said they kept a diary regularly, wrote that in some stages of the illness process it was difficult to concentrate on writing, meaning that the physical and psychological suffering caused by cancer made people silent:

Päiväkirjoistani (pidän päiväkirjaa yhä) siltä ajalta en löydä ainutakaan merkintää. Ajalta, jolloin olin menettää äitini, on kuin vuotta 1986 en niiden mukaan olisi elänytään. (085)

From my diaries (I still keep a diary) of that period I find no entries. At the time I was about to lose my mother, I did not exist in 1986 according to the diaries. (085)

Muistikirjassani on kahdeksan päivän valkoinen väli. Sen ajan sivuilta löydän yhden sanan, piinaviikko. Sana kaikkineen kuvaa näitä hivuttavan tuskan täyttämiä päiviä. Ajatukset kiersivät samaa harmaata rataa. En tiennyt mitä tehdä, miten olla. Olin kuin naulittu olevaan tilaan.

In my calendar is a white gap of eight days. From the pages of this period I found only one phrase: “a torture week”. These words apparently described all those days, filled with spleen. Ideas whirled along the same grey path. I did not know how to be or what to do. I was, like, pegged into this situation. (101)

For many participants, one of the motivations for sharing individual experiences was the fact that they wanted to help and support other cancer patients (194, 260, 354, 390, etc.). Despite the fact that, according to sociocultural expectations cancer signifies only negative experiences, for many writers the individual experience proved to be

empowering in many ways. Linda M. Hunt, an American anthropologist who has analysed the illness stories of Mexican cancer patients, has produced similar results. She has noted by the same token that in the course of rebuilding a workable image of themselves, the world, and their place in it, patients generate narratives that forge an identity around patient-hood in ways that negotiate issues of social empowerment (Hunt 2000, 92). The ideas presented in Finnish cancer patients' writings support Hunt's statement, revealing that despite its devastating impact in many ways, cancer changes patients' lives to become more positive by opening new perspectives and possibilities: "*Nyt – jälkeinpäin – olen kiitollinen tästä syöpäkokemuksestani. Se kypsytti minua ihmisenä. Vaikea sairauskin voi olla elämää rikastuttava kokemus!*" "Now – afterwards – I am grateful for this cancer experience. It changed me as a person. A serious illness can also be an life enriching experience" (079). Another respondent has even used rhyme to express this feeling (090):

*Niin kaartuu ihmisen elämänkaari,
syöpäkin voi olla siinä saari,*

*josta nousee ilon elämänpuu,
jonka voimalla sydän
avautuukokemaan,
mitä on onni, autuus,*

elämä, kaikki sen salaisuus.

So bends the human lifebow,
where even cancer can be an
island,
where grows the life-tree of joy,
which has the power to open up
hearts,
to experience, what is happiness,
beatitude,
life with its all secrets.

Respondents wish to express the fact that, despite cancer, their lives continue. Compared to other situations, their individual sorrow and suffering can only be minor:

Opettihan sairaus myös muistamaan, että mikään tässä elämässä ei ole itsestään selvää ja tänään on loppuelämämme ensimmäinen päivä. Tämä on järkyttävällä, mykistävällä tavalla tullut todeksi kirjoittaessani tätä 28.9.94 jolloin autolautta Estonia upposi Utön lähistöllä ja yli 800 ihmistä hukkuu. Se on ollut niin valtava shokki, että sitä ei vielä pysty täysin tajuamaan ja tietoa sulattamaan.

The illness taught me to keep in mind that nothing in this life is self-evident and today is the first day of our remaining life. This has become evident in a shocking, silencing way as I write this on 28.9.94, when the Estonia ship sank near Utö and more than 800 people drowned with it. This has been such a great shock that one cannot really understand it and digest the knowledge. (265)

However, to attain such understanding needs time, certain personal qualities, motivation and support, and so composing a personal cancer narrative may be helpful in reaching such conclusions. In his significant essay *Life in Quest of Narrative*, Paul Ricoeur has stated that composing a life story is a mediation between man and world (referentiality), between man and man (communicability) and between man and himself (self-understanding) (Ricoeur 1991, 27–28). Because of various levels of dialogic imagery present in cancer patients' writings, the narratives also tackle, in addition to the illness experience, several other important aspects connected to human life: everyday living, family and work, human relationships and other meaningful themes that have gained significance during the respondents' lives:

Mitä enemmän olen aina tutkinut kirjoitelmaani, sitä enemmän on tullolla aivojen takaosassa ruvennut kytämään kauhea tietoisuus, että se on aivan väärin kirjoitettu! Kirjoitan aiheesta "Kun sairastuin syöpään." Ja mitä minä teen! Kirjoitan laveasti Lappohjasta, koulusta, keilauksesta, perheestä jne. Toivoton tapaus!

The more I have studied my writing, the more I get the terrible feeling in my head that this is written totally in the wrong manner. I write about the theme, "when I fell ill with cancer" and what do I do? I talk about northern Lapland, school, bowling, family, etc. A hopeless case! (060)

Participants composed their writing in the hope of offering a different interpretation of the cancer experience and thus confront the socioculturally agreed image. The given motivations for writing point out that in the cancer narratives the respondent's desire to share the cancer experience is mediated somewhat differently because it is without the fear of being (mis)judged by society. Discussing the meaning of writing compared to oral communications, Paul Ricoeur has remarked that issues that become fixed by writing represent a discourse that could be spoken, but become presented in writing because they are not, nor can they be, communicated orally. Considering the meaning of writing from the cancer patient's point of view, the following statement from Ricoeur is crucial: "Fixation by writing takes the very place of speech, occurring at the site where speech could have emerged" (Ricoeur 1981, 146). This statement helps us to interpret and point out the main reasons why people choose to write about their illness experience. Firstly, writing is a possibility for self-expression. Secondly, people write instead of speaking because they feel that it is not acceptable to share

their cancer experience in oral communication. Thirdly, composing a narrative allows mediation of the individual experience in the desired way, thus writing functions as meaningful for writers and at the same time formulates a particular experience for their readers.

Consequently, the main motivation for composing cancer narratives may be interpreted as the cancer patient's desire to receive some responsive understanding from other people; and also to receive this from institutions unfamiliar with the cancer experience and its meaning on the individual level. Where such understanding appears unachievable in everyday communication, writing becomes an alternative path.

Inner narrative

Sigmund Freud began to approach and analyse his patients based on their narratives, and since that time many psychologists and sociologists have suggested that one possible method of identity alteration is by renewing one's life story (Brockmeier 1997, 178). It is, of course, a debatable assumption that everyone has a lifestory and that illness does indeed become interpreted as the crucial event that makes us re-examine our existence. We must bear in mind that only the verbalisation and interpretation of bodily events makes one's life a narrative, not the events themselves, and not everyone is eager to interpret his or her own life.

Concerning health and illness, the socioculturally accepted idea is that if we take care of our bodily condition and follow culturally accepted norms, we stay healthy. In everyday life many people experience a mismatch between such a belief and personal health. In particular, people with cancer suddenly notice that 'health' has turned to 'illness'. We may ask how, in such a situation, is one's life influenced if the feeling of fitness is lost and reality confronts personal identity within a changed social setting (Jacobson-Widding 1983, 14)? To become a part of a renewed social setting, or illness discourse, the individual has to adopt new roles, such as that of patient, and learn a new vocabulary in order to discuss the illness and its treatments. The illness also influences an individual's social and economic situation. Therefore, a person who is ill, is often forced to adapt his or her past behaviour and activities because of a radically changed physical condition or social position, and to find new meanings with which to continue life

(Mathieson & Stam 1995, 283–306). On an individual level, the period of falling ill and of being ill is full of alterations, questions and hesitations, and may be approached as an inner negotiation process.

Linda Hunt has proposed that having cancer requires mobilisation of resources for treatment, eliciting assistance for patient care, and renegotiation of the patient's privileges and obligations within familiar and other social hierarchies. Therefore, shifts in a person's identity when he or she has cancer, emerge in the context of the larger social framework, subsuming questions of domination and subordination (Hunt 2000, 91). This is a complex process of evaluation that may be completed in different ways, such as climbing a mountain, if physical condition and treatment allow, taking a year off work, finding a religious road, painting a picture, etc. There are several possible ways in which to renegotiate the self in an appropriate way, depending on the course of the illness and its impact on an individual's life.

Above all the inner negotiation process is an imaginary dialogue between the individual and the self. This is a dynamic process, as the individual, as well as the social, aspects have ongoing effects on people and their lives. The Finnish sociologist Vilma Hänninen has written that people's inner negotiation process is affected by a situation that is constantly in alteration. The situation changes if people act, but it also changes if they do not. The situation is based on facts, and thinking or acting may not change it, although the situation may be interpreted in various ways (Hänninen 2000, 21–22). The person suffering from a serious illness (willing or not) is challenged to examine their individual life-course before the illness, and accordingly he or she must negotiate the outcome of their particular findings. An individual's ability, and will, to analyse and interpret the constantly changing situations of the illness experience, affects the process of negotiation with the self and the (possible) formation of the inner narrative.

We may suppose that the process of self-understanding, or inner negotiation, initially takes place in pre-narratives that are composed, and exist in their complexity, in human minds. Pre-narratives, or inner narratives, are understood as a process in which the person interprets the events of life relative to the opportunities offered by the current situation. For example, Vilma Hänninen has defined inner narrative (*sisäinen tarina*) as a complex process in which the general and individual, symbolic and material, linguistic and non-linguistic, public

and private, meet, and in which new meanings are given (Hänninen 2000, 21). If we agree that such inner narratives exist, it is important to point out their difference in comparison to written narratives.

The main problem here seems to be with grasping the inner narrative. How do we, as outsiders, gain access to information preserved in inner narratives? This seems impossible without having people expressing their inner feelings, which again is an entirely different situation. Although the cancer patients analysed here demonstrate that during the writing process the inner negotiation process continues, written self-expression has to be approached as a public performance. Even if the externalisation of memory may be a purely internal process, from the moment we articulate or write, we express our experiences and memories, and therefore we communicate with others (Fentress & Wickham 1992, 26). Accordingly, written texts, unlike inner narratives, correspond to the public speech act, and thus are invariably influenced by various expectations arising from the subject of cancer and from self-expression in the written manner. When analysing such materials, it is important to bear in mind the fact that writing is composed with regard for potential readers. Because writing becomes the opportunity to share individual knowledge, experience and feelings with others, it is a significant continuation of the inner negotiation process.

The cancer narrative as a ‘key narrative’

When composing a narrative, people verbalise their experience for themselves and for others. The expressive value relating to the course of an individual’s illness makes cancer narratives “individually intentional” (Bakhtin 1981, 289). In Finnish culture, having cancer is strongly connected with images of death and dying, and this means that cancer patients’ writing is, in many ways, influenced by this culturally accepted idea. We may suggest that the cancer experience divides the individual life-story into two periods – before and after. If cancer is considered a dominant event in a person’s life, then cancer narratives may be viewed as plots in which cancer related experience generates the “key narrative” (Lehmann 2007, 198). Because of its fatal influence on human life, the process of falling ill with a life threatening illness is as significant as the experiences of war, deportation, emigration, and other pivotal events common to the human experience. In cancer

narratives, particularly when playing the culturally stigmatised cancer patient's role, people are forced into a situation in which personal identity becomes loose in various ways. The cultural stigma of cancer puts cancer patients under psychological pressure. Biomedical treatments add physical suffering, while at the same time leaving patients alone with their individual concerns. The Finnish folklorist Annikki Kaivola-Begenhøj has implied that one person may have several key narratives, although the experience of losing control of one's own life is understandably one that can never be forgotten (Kaivola-Begenhøj 2006, 41). Individual sorrow at hearing the diagnosis of cancer, and the struggle of regaining control over one's life, could be defined as the central issues in cancer patients' key narratives.

Because of cancer's lethal image, cancer key narratives may be described as following the inner negotiation process in which the sufferer becomes familiar with the idea of dying:

Olin kokenut selvän lähtölaskentani alkaneen siitä hetkestä, kun sain tiedon syövästä. Aikaisemmin kokemani vaikeat sairaudet olivat jo opettaneet minulle paljon, mutta ne eivät olleet sillä tavoin henkeä uhkaavia kuin syöpä.

I felt that a countdown began when I heard about cancer. The serious illnesses that I had experienced before had already taught me a lot, but these were not in that way as life-threatening as cancer. (331)

According to the model proposed by Swiss-born psychiatrist Elisabeth Kübler-Ross, this process includes the phases of shock, denial, anger, trade, depression and finally acceptance (Kübler-Ross, 1973; see also Myllykoski 1981, 38). The model, presenting the inner negotiation process characteristic to people with a lethal disease, is well suited to the construction of a basic structural model for the cancer narratives under observation here.

The course of the pathological drama

Shock ⇔ Denial ⇔ Anger ⇔ Trade ⇔ Depression ⇔ Acceptance ⇔

Figure 10. The stages of inner negotiation

In life, of course, all analytical models have secondary importance. The American physician and anthropologist Arthur Kleinman has demonstrated that in Western society the person with cancer continuously returns to the idea of dying in changing situations (Kleinman 1988, 147–149). According to the writings analysed here, people experience phases of shock, denial, anger, trade, depression and acceptance repeatedly; meaning that in the inner narrative, accepting the idea of dying must be continuously negotiated. Cancer narratives reflecting selected parts of the inner narrative demonstrate that when being confronted with a fatal illness it takes time to reach a point where a person accepts that life will not last forever. Furthermore, even if people accept having cancer or being terminally ill, it does not mean that they stop fighting for their lives. Typical to key narratives is the understanding that people reach about how to cope. This kind of awareness makes people more tolerant and unwearied:

Syöpää ei voi koskaan unohtaa, se seuraa mukana selkärepussa koko elämän. Mutta sinuksi tuleminen sairautensa kanssa on tärkeä asia, mutta aikaa vievä prosessi. Jatkuva muisto on fyysinen puute/erilaisuus, en ole enää koskaan sama minä. Enkä ihmisenä ole sama, kuin olin ennen syöpää. Tällä en tarkoita että se olisi pelkästään huono asia. Todellinen kasvunpaikka tämä sairaus on ollut. Elämässä on usein vaihtoehtoja valita elämänpolkuja. Sairastuessaan ei paljon tarjoilla mahdollisuuksia ja vaihtoehtoja, on otettava vastaan mitä tulevan pitää. Haluisi tai ei.

I can never forget cancer as it follows me in the rucksack all my life. Coping with illness is an important thing, but it takes time. The continuous memory is the physical difference, as I will never be the same. And as an individual I will not be as I was before I fell ill with cancer. I do not mean that this would only be a bad place. This illness has been a reason for growth. There are often possibilities and opportunities available along the life path. When ill there are not many possibilities or opportunities, one must accept what is given. It does not matter if you want to or not. (046)

This example demonstrates that although people cope with the idea of having cancer they will always carry this experience in their minds. This leads us to the following issue affecting the composition of cancer narratives, namely, the question of remembering and memory.

Remembering and memory

Writing a narrative is closely associated with the process of remembering and memory. At the time that psychologist Endel Tulving first introduced the types of episodic and semantic memory that relate to human action (Tulving 2002, 3–5), many folklorists were interested in memory and its impact on the narrative process. For a while, division between different memory types became predominantly attractive in narrative research. This approach was foremost employed to follow the processes by which personal experience was turned into collective tradition. It was an attempt to explain how an individual experience is altered by the collective tradition, and formed into a folklore product. Accordingly, in the folkloristic approach, remembering became interpreted as a social event in which reminiscence is simultaneously affected by various factors, not only the psychological regularities related to remembering (Chafe 1977, 220–224, Siikala 1990, 111–112).

In recent years, mainly since the shift to autobiographical narratives, the interest of folklorists has moved towards memories and reminiscences as a folklore genre. The Finnish word *muistitieto* (lit: ‘memory data’) refers to remembered knowledge (Fingerroos & Peltonen 2008, 8). Unfortunately, the affect of episodic or selective memory on the narration process has been left to some extent without attention in this context. The individual ability to remember has a crucial role in narrating past events, while it makes possible a mental journey by ‘bending’ time’s linearly moving arrow into a loop (Tulving 2002, 2). Particularly in critical situations, in which the self is loose or even lost, an individual’s ability to remember and memorise is different, and thus significant in interpreting the formation of key narratives and the individual narration concerning cancer experiences.

The capacity of working memory is limited and so people select and organise their knowledge into mental units. As a result, some of the events we experience disappear, others are recallable and some stay vivid forever (Ericsson & Kintsch 1995, 211f.). According to the material at hand, the respondents feel differently about their individual ability to remember various cancer related events. This means that their conscious awareness regarding past events, and recalling them, is very different, which naturally affects the process of written self-expression.

Some respondents say that as the years pass, the cancer experience has lost its primary significance, while others say that the individual memories connected with cancer will never fade. The following examples, from the co-letters, mediate adequately the lack of individual awareness of emotionally challenging, lived situations (where ‘awareness’ is defined as the ability to notice and understand). In addition, they show the continuous adaptation of personal awareness of the past in an ongoing, changing, situation:

Elämän tarinat ja niissä eletyt kokemukset alkavat aina jostakin tunteesta kasvaen ja muuttuen koko ajan toiseen muotoon ja toiseen tunteeseen käyden läpi varmaankin psykologisia lainalaisuuksia, jotka on helppo tunnistaa ja nähdä jälkikäteen, mutta jotka itse elettyinä hetkinä ovat niin voimakkaita ja ajassa kiinni olevia, että on täysi mahdottomuus käsittää edes niiden olemassaoloa: niinpä rakkautta seuraa usein kyllästyminen, sitten inho, välinpitämättömyys ja lopulta ehkä unohtuksen armo. Joskus tunteet myös päättyvät jonnekin ikään kuin “tunteiden hautausmaalle” tehtyään täyden matkansa ja antavat samalla meille varmuuden kokemuksesta seuraavaa, ehkäpä samantapaista tunnetta varten. Ne ovat myös kuin sirpaleita, jotka muodostavat elämän saviruukun: erikseen palaset voivat viehättää muodollaan tai värillään hetken, mutta vain yhdessä ne kokoavat saviruukun; niillä on siis tarkoitus, olkoonkin että ne saattavat olla hyvinkin mitättömiä. Tämä tarina kertoo sellaisista tunteista, jotka eivät vielä ole päättäneet kiertokulkuansa.

Life stories and the experiences lived in them always begin to grow out from some sort of feelings, and change their form all the time to other feeling, possibly going through some laws of psychology that are easy to recognise and see afterwards; but during the lived moments they are so powerful and fixed by time that it is impossible to understand even their existence. Indeed, falling in love often continues with being fed up, hatred, ignorance and later perhaps the mercy of forgetting. Sometimes feelings also end up somewhere like ‘the graveyard of feelings’ after making a full turn and giving us the confidence for forthcoming experience, and perhaps for similar feelings. These are also like bits and pieces that form a clay bowl: they have meaning, although this may be quite insignificant. This story tells of such feelings that have not yet ended their circular journey. (401)

Päiväkirjasta: “Minulta meni muisti. Unohtui, missä on osaston wc, miten mennään laboratorioon. Kädet tärisivät lakkaamatta, katse tuijottaa. En voi edes sanoa, että kuolen tähän tuskaan.” Päiväkirjamerkinnet tästä eteenpäin ovat hajanaisia, lyhyitä. Niitä on vähän. Valokuvia

osastolta on jonkun verran ja Heidillä kirjeitä osastolla tutuksi tulleilta ystäviltä. Dokumentteja on perin vähän. Silti sen kaiken muistaa. Tuska palaa uudelleen sydämeen, kun siitä puhuu tai ajattelee.

From my diary: "I lost my memory. I forgot where the toilet is, and how one goes to the lavatory. My hands were shaking constantly. I stare. I can't even tell if I will die from this suffering." The notes in my diary from this moment on are severe, short. There are few of them. There are some pictures from the department and H. has some letters from those she learned to know there. There are few documents available. However, everything stays in the mind. The sorrow returns to my hart, as I talk or think about it. (406)

Regarding cancer narratives, it is significant that our memory makes possible time travel through events connected by subjective time and space. This, however, is connected with the particular person and his or her individual auto-noetic (looking at the world) awareness in the past. This awareness of the past, in the past, enables a person to recall it in the present, which in the context of the writing competition, enables conscious recollection of past events. Such recollection creates time travel from the present to the past, allowing one to re-experience one's own previous experiences (Tulving 2002, 6). Through the given reasoning, I wish to point out that this kind of selectiveness based on individual ability to memorise, remember and recollect, strongly affects the writing process. The recollection of individual memories has little to do with listing the lived events. This is merely an active process in which events from the past evoke strong emotions and new thoughts. For individuals, such recollection may be challenging, although psychologically beneficial. For the study of materials representing the process of such recollection, this means the events and themes described in cancer narratives have, again, lost some of their accuracy when connected to reality, whereas in the context of cancer experience the kind of 'forgetting' that may be interpreted as intentional also becomes important.

Detecting 'meaningful silence'

When analysing cancer narratives it is also necessary to analyse the limitations set on composing a written narrative. In Finland, as in many other societies, it is uncommon to share intimate or revealing

topics with others (Linde 1993, 47–48). Discussing illness is a culturally stigmatised act, similar to discussing such topics as loneliness, poverty, loss of work and ageing (Varis 1998, 177). The narratives under examination point out a very important social aspect of cancer: in many ways the illness stigmatises its carrier. Consequently, people do not know how they should act, and whether they are ‘allowed’ to discuss their illness publicly. If they choose to talk about it openly, they risk loss of social position, respect of friends, and contacts with acquaintances. According to the analysed writings such societal misjudgements are unfortunately not uncommon among Finns (see Chapter 5). For that reason, many cancer patients intending to avoid these inconvenient situations, and possible misjudgements, decide to be silent and ignore the topic in everyday conversation.

I have argued that since discussing cancer related problems openly is experienced as objectionable, cancer patients may see writing as a liberating opportunity to express their inner concerns (Hawkins 1999, 35). The problem is also that through writing, which is mediating individual experience and social and cultural attitudes and beliefs, people have to reveal themselves. This means that they have to decide how to write about significant aspects of their illness in order to avoid possible criticism and other negative reactions. In this sense, it is interesting that people write about socially and culturally significant themes. Furthermore, it is interesting to see how language and culture affect written self-expression when the writer discusses issues that are defined as marginal in everyday communication.

Ethnographic studies of language use have shown that methods of language use are not universal. The ideologies captured in language are part of cultural conceptions that are adopted during the enculturation process characteristic to a particular speech community (Och and Schieffelin 1984, 276–278). In every speech community there are certain ideas interpreted as marginal in everyday communication. Every person dealing with marginal issues is aware of them. Illness, death, suicide, sexuality, birth, bodily concerns; in addition poverty, politics, race, punishment and crimes may need careful choice of words. Members of a speech community are thought to behave according to the norms of a particular culture, including avoiding undesired words and issues that illicit unwelcome reactions and influence the culturally determined order of society. In this way, the enculturation process sets

(institutionalised) frameworks around different discourses significant in human communication.

The deliberateness of this phenomenon, guiding as it does the use of language, is an interesting issue. On an individual level, uncomfortable feelings are deeply connected to the feeling of shame and fear. The feeling of shame could be approached as the most dynamically restricted and controlled feeling in culture (Ronkainen 1999, 135). Although the feeling of shame is not in direct correlation with culturally agreed taboos, shameful issues are communicated carefully, or stay entirely unmentioned. This means that certain words, themes and issues gain the position of 'non-observable' aspects of language use, and accordingly set limitations on written self-expression. The awareness of such limitations creates an interesting situation in which the context or discourse itself is non-observable, while the consequences remain evident (van Dijk 2006, 164).

Based on the cancer narratives, it is only possible to guess the extent to which cancer patients' experiences are covered by the 'meaningful silence' set by the ideologies mediated by language. Fortunately, when observing the numerous textual accounts, it is possible to recognise words, episodes and themes that appear to be marginal, or are somewhat complicated to tackle. Our understanding of the limitations that cover cancer communication helps us understand the reasons why talking about cancer is difficult in everyday communication. Equally, it helps us to comprehend why writing about personal cancer experiences has been both experienced and described by respondents as an extremely beneficial, even liberating process. Consequently, despite the culturally bound, and language-based, limitations set on cancer related discussion, the opportunity to express oneself and to mediate the consequences of being diagnosed with, and having, cancer on individual, social and societal levels has resulted in a collection of texts that reflect human minds and reasoning, forming a remarkable ethnographic context within which to study the meaning of cancer.

The personal voice and culturally bound representations

Writing a story is not only about listing events. Writing a story is so much more. Writing, as with all other methods of self expression, is a

communicative act full of meaning. In the search for better communication, people form their individual stories in accordance with traditional or national norms of written utterance (Bakhtin 1986, 65). This means that writers do not share all of the inner concerns that might have affected them during their illness period. When writing, they activate their episodic memory and recall past events and episodes that evoke strong feelings and new ideas. When composing their stories, the recalled events and episodes become interpreted, and will be altered according to the social norms and rules that govern the production of a fixed narrative.

The writer must carefully consider the rules of performance (written self-expression), soci(et)al expectations (readers) and the general social and cultural context (discourse). Although people follow individual narrative patterns, depending on how they have been affected by their personal experience, the written narrative becomes evaluated through the cultural understanding of successful writing (communication). This leads to writers making choices on structural, vocabulary and expressional levels, and therefore people construct their narratives based on their own writing skills, which are themselves constantly being compared with the individual's image of 'proper' written narrative:

Tässä tämä sotkuinen sepustukseni, lähetän tämän kuitenkin kun ette täydellistä vaatineetkaan. Tämän kirjoitti vanha ihminen 1920 syntynyt, vanhalla koneella ja yhdellä sormella. Oletteko hyviä ja korjaatte kirjoitus ja ajatus virheet ja poistakaa tarpeettomat.

Here comes my messy letter. I will send this, as you did not ask for perfect writing. An old person, born in 1920, has written these texts with an old typewriter and with one finger. Please, be so kind as to correct my writing and thinking faults and remove parts that are unnecessary. (023)

As every cancer experience is to some extent unique, cancer narratives concentrate on important themes and issues that are personally significant for the respondent. On the other hand, because of the culturally preset rules that guide the process of written self-expression, people select themes and issues for discussions that might also be significant for others, particularly the addressee reading cancer narratives. This, again, means that themes that are selected for writing, and which are thus often repeated, have a particular significance in the context of cancer experience in the ethnographic sense.

When the Danish folklorist Bengt Holbek proposed his idea in connection with the interpretation of fairytales (Holbek 1987) it caused a revolution in folk narrative research. Human scientists, among them folklorists, asked countless questions about the connections between folk tales and reality. Holbek's colleague Michèle Simonsen's criticism of those interpretations points out a very important aspect of narrative research: "All those scholars seem to forget that a tale is also a work of art, which partly follows its own laws, and that the relationship between reality and fiction is not a direct reflection, but a complex process of transformations" (Simonsen 1993, 124). Simonsen points out a significant aspect that often stays unnoticed in studies adopting the modern narrative approach. Although the participants intend to make their narratives as 'accurate' as possible, accuracy is impossible because of the inner rules of composing a narrative, as well as the individual, linguistic and cultural limitations that govern narratives. Accordingly, some writers clearly make use of their written self-expression skills and compose truly enjoyable plots full of drama, comedy and masterful confrontations. Other writings are impulsive and confusing, even though the writer's main ideas and aims are still graspable.

Folklorists and other narrative researchers have persistently pointed out that composing a narrative is not based simply on individual knowledge and experience but is framed and modified by cultural and socio-historical discourse. Dell Hymes has called it a personal voice (Hymes 1985, 391), and says that by choosing, we communicate something personal as well as cultural, if we have the skills to recognise it. In his important work *The Dialogic Imagination* Mikhail Bakhtin has defined the diversity and stratification of voices in written texts as heteroglossia (Bakhtin 1981, 263). According to Bakhtin the value-laden way of self-expression may be described as a permanent dialogism fulfilled with intentional (intended) words. Therefore, written cancer narratives must be viewed as personal experience narratives, but also as intended social speech acts targeted to the organisers of writing competition, cancer patients, medical practitioners, other decision makers, etc., with a particular goal.

The status of written cancer narratives

An important problem when analysing written cancer narratives is that of the status of the text. Namely, what factors ‘fix’ the text so that the intended meaning may be interpreted? In his study on text and textuality, William Hanks (1989) has pointed out that the status of text consists of at least five significant parts: the boundaries of texts, the “centring” of text within some interpretative matrix, text as a performance, the reception of the text, and the construction of synchronicity (Hanks 1989, 103–113). Here, concerning the status of cancer narratives, I observe the first three of the five parts suggested by Hanks. The construction of textual synchronicity depends on social histories, which I have already considered above; and to the fourth part, regarding the reception of the text, I will come at the end of this chapter. The first three parts, however, are useful notions with which to point out the importance of schematic aspects governing the attempts to gain the ‘intended’ meanings appearing in the texts.

The narrative schema proposed first by William Labov and Joshua Waletzky (1967), and later in more detail by Labov alone (1972), has been one of the central theoretical approaches influencing the folklorist and other narrative researchers, while also drawing the folklorist’s attention to structural segments (episodes) such as abstract, orientation, complicating action, evaluation, and coda in personal experience narratives and other folklore genres. The Finnish folklorist Annikki Kaivola-Bregenhøj has said of the adoption of Labov’s schema, resulting in a folkloristic narrative analysis understanding, that, “the schemes or conventions of specific genres do not guide the production of pure traditional narratives but narrative in general” (Kaivola-Bregenhøj 1996, 36). The schematic analysis of narratives points out two important aspects, first, that a narrative is a series of episodes (the details vary from one researcher to another), (Kaivola-Bregenhøj 1996, 34–36; Siikala 1990, 38–40; van Dijk 1980, 113–115; Chafe 1979, 26; Kintsch 1977, 38; Rumelhart 1975, 222), and, secondly, that different genres have their own (traditional) criteria and limitations governing their content and performance (Siikala & Siikala 2005, 133). As I have pointed out above, this is an important concept when considering the analysis of thematic narratives and the understanding of their significance as ethnographic sources.

The first part of the status criteria stated by Hanks is certainly most important to textual analysis as it endeavours to define the borders of the object under study. According to Hanks, the boundaries of a text can be defined, along with its difference from non-text. In that case, the borders of the selected writings are best defined by the text's narrative nature. Namely that creation of a narrative also creates the difference between text describing events (narration) and the lived events (experience) themselves. Even if I have discussed a certain incompleteness among the cancer narratives, we could suppose that texts are never finished (Ingarden 1973, 251), and thus, the 'fixed' form of the written text gives the selected narratives their finished status. Putting focus on the schematic status of textual works forces, according to Hanks, a rethink of the idea that boundaries between what belongs to a text, and what does not, are fixed. Hanks emphasises that textual boundaries may be dialectically constituted in the interplay between schematic and concretised moments, including the 'black spots' in the schema. These represent "the spaces between portions of a broken line" that constantly remind researchers "to connect the dots and fill in the meaning" that one needs in order to interpret (Hanks 1989, 105). In the schematic sense, the cancer narratives' boundaries are indeterminate, with the main reason for that laying in intertextual and extratextual factors that are responsible for the multitude of voices present in every text. In order to understand the 'voicing' in any particular text (Hanks 1989, 114) it is necessary to be aware of aspects that influence the respondent's intended meanings within a text.

The second part proposed in Hanks' work, the 'centring' of text within some interpretative matrix, raises an equally interesting question about the status of the materials under study here. The individual cancer experience is determined by temporal and spatial factors within a certain context, as mediated by the written texts. To understand this we must be aware of the context as defined by the dialogism between socio-historical development and sociocultural discourse. When the context that contextualises the text (narrative) becomes defined, it is easier to concentrate on analysing episodes that mediate significant events and activities. Accordingly, Hanks has suggested that "these structures have in common that they are relatively fixed configurations of information corresponding to actionable wholes (such as types of events, activities), global scenes, sequential routines, and other extended domains of reference" (Hanks 1989, 110). Thus, here again,

the schematic structure and its compositional parts leads towards the understanding of meanings that are fixed in text.

The fact that the thematic writings studied here were written at the request of the folklore archive is also a significant factor relating to centring in thematic narratives. Therefore, it is interesting to examine how the context of the writing competition influenced the final texts. This influence has been analysed in Ulla-Maija Peltonen's (1996) work *Punakapinan muistot* (Memories of the Civil War) and in Pauliina Latvala's (2005) book *Katse menneisyyteen* (A Glimpse Into the Past). Pauliina Latvala has suggested that the Folklore Archive at the Finnish Literary Society has a traditional role as a 'paternal' institution that gathers oral history and the individual experiences of Finns. Latvala points out that, although respondents may have very different understandings of how a proper response to a folklore archive should be composed, the idea of composing a text for archive has a certain impact on a respondent's identity (Latvala 2005, 34–35). Foremost among these, the context of the writing competition influences the ideologies of the texts composed. In the case of the cancer narrative, this ideology is influenced by the sociocultural and medical context, detectable in the ways in which people comment on sociocultural attitudes towards cancer patients and patient-doctor communication in healthcare institutions.

From the point of view of self-expression, interpreted here as the intended social speech act, the status of cancer narrative is on the whole very important. In addition to the psychological and constructive value (inner negotiation) fixed in the writing process, the importance of cancer narratives comes from their status as an ethnographic source sharing sociocultural attitudes and ideas about cancer. Compared to the ethnomedical sources used in this work, authorial speech in cancer narratives adds to the written archive sources a multitude of voices important in comprehending the central question of this work: What is going on?

Cancer narrative as 'a thematic whole'

John Dorst has written that, "no genre exists outside of the dense thickets of citation, commentary, resistance approval, mimicry, parody, etc., that constitute the responses of other points of view". He continues with Dell Hymes' idea that generic interactions are ongo-

ing accomplishments, often variable or uncertain in outcome; for the most part they involve the subconscious genres of everyday discourse (Dorst 1983, 414; Hymes 1975, 351–352). Dorst's suggestion builds on Bakhtin's idea that secondary speech genres (mainly written) absorb various primary (simple) genres during their formation or generation (Bakhtin 1986, 61).

Cancer patients' writings include numerous conventional discourse genres or primary genres that are particularly attractive for folklorists. Within the secondary narratives are proverbs, sayings, predictions, dreams, jokes, and various beliefs concerning cancer that carry many significant cultural values. From the ethnomedical point of view cancer narratives describe popular beliefs about the origin of cancer, the problems with defining the illness, and the complexity of prevention techniques. Furthermore, cancer patients' writings communicate the sociocultural expectations confronting cancer patients, problems with doctor-patient relationships, and the challenges faced in the attempt to adopt the practices of self-help. Equally meaningful are references and citations from various books, calendars and diaries, as well the biblical quotations that have gained significance during the individual's illness course; likewise the wide range of poems written by cancer patients expressing their deepest feelings are also tempting for folkloristic enquiry. All these simple genres invite immediate folkloristic investigation, although Bakhtin's warning finger points at us. He points out that the difference between primary and secondary (ideological) genres is very great, and indeed fundamental, although this is precisely why the nature of the utterance should be revealed and defined through analysis of both types (Bakhtin 1986, 62).

According to Bakhtin's interpretation, a one sided orientation toward primary genres inevitably leads to vulgarisation of the entire problem. The very interrelations between primary and secondary genres and the process of historical formation of the latter sheds light on the nature of utterance (and above all on the complex problem of the interrelations between language, ideology and worldview). In his article about discourse genres in theory and practice, William Hanks examined genres as a part of conventional discourse. He claims that the use of genres is foremost dependent on one's linguistic and communicative *habitus* (Hanks 1989, 112–113; Hanks 1987, 670, 687–688). As with genre and cultural convention, the ability to recognise discourse genres lies mainly with the reader or addressee (Hanks 1987, 682;

Bakhtin 1986, 95–96). Where the frameworks of cultural understanding are set correctly, the reader acknowledges the emergence and the concept of genre. Therefore, it is very important that cancer narratives as thematic units become interpreted and analysed as a whole, meaning that when approaching cancer narratives it is important to be aware of numerous internal and external aspects regarding these narratives. To understand written cancer narratives one has to be aware of the textual qualities, the writer's intentions regarding the use of different genres, collecting aims and circumstances, the socio-historical and cultural frameworks of the particular discourse. Furthermore, one has to be aware of the consequences linked to the topic in order to recognise if something 'non-observable' is uttered as well.

Conclusions

Narrative is a communicative tool and thus the composition of narrative is constantly influenced by sociocultural surroundings and norms, as well as individual reasoning, utterance skills and individual ability to remember and recall individual events. Thus, it is important to remember that narratives do not exist *per se*. Narrative is an act of self-expression that represents the lived experience containing intended and thus meaningful acts. Accordingly, narrative events become selected by the narrator and placed in an optional spatial and temporal dimension. The respondent chooses the characters and paints the necessary oppositions to make the desired point. Considering this, the cancer narratives analysed here are fictive representations linked with some aspects of reality. Theoretically, all the events, thoughts and emotions described in cancer narratives belong to the narrative world.

Despite their fictive character, cancer narratives form an excellent ethnographic source that allows the examination of the personal, societal and sociocultural meanings of cancer. Like all personal experience narratives, cancer narratives mediate the individual's inner thoughts and everyday communication, as well as socioculturally agreed expectations. Thus, cancer narratives may be approached as representations of cancer patients' inner negotiation, influenced and framed by everyday action and socioculturally agreed expectation.

When dealing with narratives, one should always have in mind that any narrative that becomes verbalised and expressed, is an in-

terpretation that becomes influenced by the cultural expectations set on the communicative act and the particular discourse. Furthermore, the writing process, in a similar way to storytelling, consists of small individual choices. The writer chooses what is worth sharing and what is insignificant. In this context, I want to emphasise that the benefits of written text, as opposed to oral performance, lay in the writer's opportunity to consider his or her self-expression carefully and, based on individual linguistic and communicative *habitus*, present narratives in their 'fixed' form in a particular situation. Foremost, the act of self-expression is a conscious process and thus the generated narratives may be analysed as fictive, or 'near' to individual experience. This holds true even if, in reality, the individual interpretations of one's feelings, experiences and thoughts lose their meaning as time passes. Because of continuous changes in situations that affects human life, previous interpretations become overlooked and, in the case of persisting individual value, re-interpreted.

Before moving further, I emphasise that narrative based study cannot concentrate only on narrative content. Above all, any scholar dealing with thematic narratives should consider the interrelation of primary and secondary genres in order to understand a respondent's intentions and the significance of the given representations under study. More importantly, one should be aware of the ethnographic context of a particular situation, while the sociocultural setting or discourse captured in thematic writings is far more stable than individual interpretation based on lived experience.

WRITTEN CANCER NARRATIVES

An Ethnomedical Study of Cancer Patients' Thoughts, Emotions and Experiences

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<http://www.folklore.ee/ri/pubte/ee/sator/sator10/>

ISBN 978-9949-490-31-8

Tartu 2012

Printed version: Piret Paal. Written Cancer Narratives.
An Ethnomedical Study of Cancer Patients' Thoughts, Emotions
and Experiences. SATOR 10.
Tartu & Helsinki 2010

Author: Piret Paal

Series editor: Mare Kõiva

Language editor: Daniel Edward Allen

Cover design: Tero Leponiemi

Layout: Liisa Vesik

HTML: Diana Kahre

Academic dissertation to be publicly discussed, by due permission of the Faculty of Arts at the University of Helsinki in Arppeanum lecture-hall (Helsinki University Museum), on the 15th of January, 2011.

The publication is related to the target financed project SF0030181s08.

Electronic version editing is supported by ECRM04-29 Expansion of the sphere of use and introduction of the Estonian language, culture and folklore in electronic information carriers.

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Cover Tero Leponiemi